

**CCC Quality of Life Committee Meeting**  
Thursday, October 13, 2005 9:00 am-12:30 pm  
American Cancer Society, Phoenix, 2929 E Thomas Road

**Meeting Minutes**

Co-Chairs: Dr. Don Brooks, Medical Oncologist (present)

Co-Chairs: Patricia Harmon, CEO, Sunstone Cancer Support Centers (present)

Members present:

Kay Kays-resides on The Wellness Community Board Of Directors, patient advocate for U of A Cancer Center. and pancreatic cancer survivor

Paula Hardison-Executive Director, The Wellness Community

Carol Harney- Executive Director, Quality of Life, ACS

Jeri Burkett- Komen Foundation, and breast cancer survivor

Pat Priniski- formerly of Hospice, specializes in oncology nursing

Brenda Keith- Research nurse, Genentech

Susan Leigh- Oncology nurse, breast cancer survivor, patient advocate, founding member, National Coalition for Cancer Survivorship, works with other national orgs.

Kathleen O'Connor- Program Director, Scottsdale Healthcare, Virginia G. Piper Cancer Center

Jennifer Womsley will not be able to serve on the QOL Committee, other members send their apologies for being unable to attend today.

Dr. Brooks presented a quick overview and recap of four objectives (QOL has 3 priorities, but will work on all 4) and strategies under each.

Paran clarified that some of the other CCC committee objectives outlined in the plan have measurable goals because those areas had baseline data. Paran also emphasized that the Quality of Life Committee can organize itself as it chooses.

Education is a critical piece of all the Cancer Plan's strategies, and Paran is working on a marketing plan to educate the public about the CCCP, which will utilize tools released by CDC in the Winter. In addition, \$40,000 in mini-grants will be made available for activities related to implementation of cancer plan priorities.

The Quality of Life Committee discussed the optimal structure for success and implementation of its goals and strategies. It was widely felt that a subcommittee model was advantageous to broaden involvement in the committee as well as to get things accomplished. Communication between members and committees was discussed as an important issue.

Committee members felt it would be important to continue seeking other partners in the community to get involved.

Paran spoke about other state's goals and strategies and their implementation tactics and committee structures. Susan Leigh asked Paran for a list of what other states have done so we could perhaps glean from their success and not reinvent the wheel.

The committee felt it would be critical for there to be communication between committees. Paran suggested that several meetings needed to occur before there would be a level of activity that would warrant collaboration between committees, but agreed that this was something CCC staff are committed to assisting coalition members with. The CCC website intends to link everyone together by posting minutes under the CCC committee sub-category at [www.azcancercontrol.gov](http://www.azcancercontrol.gov) as well as additional information.

A result of linking committees together goal eventually, is to identify cross-cutting issues between committees and to leverage what committees are doing and cross fertilize one's activities with another.

It was also suggested that committee chairs meet quarterly as a way to enhance communication, identify cross-cutting issues and enhance collaboration.

Governor Janet Napolitano was recently appointed to C-change and is on the State Cancer Plan committee. AZDHS Deputy Director Rose Connor will set up a meeting to debrief the Governor, and ideally the Governor will become more actively involved in our activities.

It was suggested that getting more political figures involved in the process would be beneficial.

Susan Leigh addressed the activity that is occurring in our suburban areas and the level of collaboration and partnership, and that there is little happening in rural communities. This needs to occur. One suggestion was a mini traveling Quality of Life program.

Susan spoke of the San Carlos Indians, and that they need simple basic information and education. Their needs are different than other communities, and we need more Native American survivors as an example that demonstrates to others that cancer is not a death sentence. Dr. Brooks mentioned that Agnes Attakaifrom U of A (Prevention Committee Co-Chair) would be good to collaborate with.

Paran thought it was important for everyone to know and participate in an important cultural competency training being offered to those participating in the CCCP. Pam Iron from Oklahoma, who has worked extensively with Native

Americans, will be presenting a workshop in January. More information forthcoming.

Paran said she was brought to Phoenix and Arizona to help increase involvement and participation from the Native American community in the plan, and that Char Hewitt is coming out to help us get Native American tribes more involved. Kathleen O'Connor talked about the health fair in Morenci that does a good job of educating the public. The Quality of Life Committee could use this as a model or seek a way to complement what they are already doing.

The Committee discussed the activities that are happening in Phoenix that bring everyone together. The Wellness Community is hosting a Cancer Walk and Resource Fair to bring all organizations, individuals and companies offering any type of cancer resource to the public to the community. They are hoping to draw attention to the CCCP with this activity, and it will be one of many collaborative ventures between all the cancer resource entities in our community. This is a community-based venture versus the Cancer Expo that occurred several years ago that had more of a national focus.

Carol Harney said that ACS' One Voice Against Cancer was another extremely worthwhile collaborative, community-wide opportunity for all those representing cancer resources to come together.

As part of raising awareness and public education, organizations should have a logo on their printed materials stating that they are part of the CCC Coalition.

It is important to look at what is already in existence and leverage off of those activities.

Objective 4.1: Increase access to the comprehensive management of acute, chronic and delayed effects of cancer and its treatments.

Strategies:

1. Develop community-directed education plan for pain-tx options.

Activity:

- a. Collaborate with AZ Pain Initiative

**Next Steps:** Find out about AZ Pain Initiative's resource directory, education plan, etc. Attend AZ Pain Initiative Meeting on Wed Oct 19 at Flinn Foundation, 8:30am-2:00pm (Paran, Taira, possibly Kay, Jeri, Pat, etc.)

Don to contact Anne to take lead on plan in order to link work from AZ Pain Initiative with CCC Coalition's efforts.

Arizona Women's Cancer Network, which has dismantled, created a database, which houses a resource directory and it is available on disk.

**Next Steps:**

Paran has a copy of the disk and what she has is for breast cancer only. Will bring it to next meeting. Don will also contact Becky Howard. Kathleen wrote grant for this project and is familiar with the database. Paula will help with revisions/updates to current directory once we have it. Paula and Kathleen will take lead on this.

Strategy 2: Create plan to increase awareness about utilization of complementary therapies for symptom mgmt.

**Activities**

- a. Educate consumers and caregivers
- b. Collaboration between providers of complementary therapies to widen geographic and programmatic reach.

**Next Steps:**

Patricia will take lead on this and possibly include other individuals who work in this area.

**Strategy 3:**

Increase grant funding opportunities to support research on QOL measures and application.

**Next steps:**

All members will look into current resources available and share with group at next meeting.

Objective 4.2: Create opportunity for optimal utilization of local, state, national resources.

**Strategy 1:****Ideas:**

1. Put together resource listing
2. Explore patient navigator programs currently in operation; this is a cross-cutting strategy with Diagnosis/Treatment Committee headed by Becky Howard. Collaborate with this committee.
3. Contact Cindy Bennette, VP of Operations, ACS to get info on patient navigators.
4. Scottsdale Healthcare-cancer coordinators
5. Sunstone in Tucson-Navigator Program, Cancer Guides
6. Look into Harold Freeman model or any literature on Patient Navigators.

**Next Steps:** Brenda Keith will work on this and Patricia will contact Marcy from Sunstone.

Strategy 2: Identify limitations of cancer care and encourage capacity to provide support services.

**Next Steps:**

Collaborate with AZ Town Hall and work with Disparities Committee on this- Contact Maria Tirado and Veronica Perez, Co-Chairs. Paula Hardison to contact Shirley Agnos to discuss AZ Comprehensive Cancer Control (CCC) as a possible topic for an AZ Town Hall meeting. The Town Hall would serve to further educate the State, involve members in rural communities, and ideally identify means to address the goals and strategies in rural communities.

Strategy 3:

Strategy 4:

**Objective 4.3:**

Increase support for health care providers and payers in directing those affected by cancer to QOL services.

Strategy 1:

Develop educational primers to educate physicians, nurses, students, etc.

**Next Steps:**

Use current resources readily available such as Cancer 101 ppt presentation and educational materials available through NCI [www.cancer.gov](http://www.cancer.gov); also contact Maria Tirado since she is the POC for NCI's Cancer Information Service in Arizona. Susan Leigh will take lead on this and contact Maria.

Patient Advocate Foundation-their role?

Getting Health Insurance Companies more involved- already have AHCCCS involved as well as Aetna.

Ideas: United Healthcare-EverCare, Blue Cross Blue Shield, Pacificare, etc.

Kathleen's comment: looking at QOL from **3 domains**:

1. Individual
2. Group
3. Community

How can we demonstrate the importance of these 3 levels in a 7-9 minute video? Other orgs or entities have used a series of videos to educate and inform on different cancer and QOL concerns.

Long-term follow-up: IOM Report will be published soon on this with respect to cancer survivorship.

Oncology nurses, physicians, patient advocates, cancer survivors-working on plan for systematic follow-up of survivors. Also, working in concert with centers

that offer clinical trials since they work with survivors and those facing or at risk for cancer.

QOL Committee supporting the pro-active patient post-treatment.

Objective 4.4:

Increase integration of palliative and hospice care into the overall cancer continuum.

**Next Steps:** Pat will work on this sub-committee. Other potential members to invite to the committee: Lean Black-Hospice of the Valley, Paul Russo-VA, Teni Bahti-Carondelet Hospice, Paul Harrington- Hospice of the Valley, Deb Hollewell-Hospice of AZ, phone: 602-678-1313

Next Meeting Date: some time in December, possibly in Tucson, TBD.

Next Meeting Objective for committee members: Each will report back on progress made with respect to objective and any contacts made thus far. Use activity matrix as needed to take notes and keep track of progress, who you contacted, etc.

Meeting Adjourned at 11:55 am